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Department of Social Protection
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Department of Social Protection

Chronic Fatigue Syndrome

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1. Overview and Definition of Chronic Fatigue Syndrome

1.1 Overview

Chronic fatigue syndrome (CFS) / myalgic encephalomyelitis (or encephalopathy) (ME) is a not uncommon, complex debilitating disorder, characterised by severe fatigue accompanied by a range of other symptoms. The disorder can be incredibly debilitating to an individual – with the effects being as disabling as multiple sclerosis, chronic heart failure or rheumatoid arthritis (Turnbull et al, 2007). Although there has been considerable research with respect to the disorder, the causes of chronic fatigue syndrome are still poorly understood (Reid et al, 2008).

Severe and persistent fatigue as been reported by up to 20% of the population (Sharpe and Wessely, 2009) but the majority of these individuals do not seek medical help with the condition. Chronic Fatigue Syndrome is a hugely disabling disease, resulting in significant individual, social and economic costs. In the US, the cost of CFS to the economy in terms of lost productivity has been estimated at $9.1 billion annually (Reynolds et al., 2004).

The fact that the disorder is not well understood has led to differing thoughts as to the nature of the disease. An older hypothesis was that the disease was of psychiatric origin. More recent thinking suggests that although the disease can be multi-factorial in aetiology, it should be regarded as a neurological disorder rather than one of purely psychiatric nature. However, psychiatric comorbidity such as depression and anxiety is common.

As well as differing thoughts on the nature and aetiology of Chronic Fatigue Syndrome, there continues to be a degree of dissent regarding terminology to describe this disorder. Historically, Chronic Fatigue Syndrome (CFS) was used interchangeably with Myalgic Encephalomyelitis (ME) although some patient groups would vehemently insist on their distinction. However the Chief Medical Officer for England in 1998 (reporting in 2002) called for a consensus to be reached on terminology and definition, suggesting that the composite term CFS/ME is used to describe what should be considered to be one condition or a spectrum of disease (Turnbull, 2007). However, representative parties still vary in name convention for this disorder. Patient groups and medical literature often refer to the condition as ME/CFS, just ME alone or Chronic Fatigue Syndrome. There is also dissent on the term ME itself – whether this should be myalgic encephalomyelitis or myalgic encephalopathy (RCPCH, 2004).

The variation in terminology is further compounded by the descriptions in the two main diagnostic classification systems - which do not represent comparable diagnostic classifications. The International Classification of Diseases - ICD-10 (WHO, 2007) – classifies the condition as a neurological disorder (G93.3) benign myalgic encephalomyelitis. The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision (DSM-IV-TR) (2000) classifies the condition as undifferentiated somatoform disorder. There is an international consensus definition in use also, to define Chronic Fatigue Syndrome.

All classifications have similar symptom descriptions, which further adds to the confusion in definition, diagnosis and classification of the disorder (Sharpe and Wessely, 2009).

Chronic Fatigue Syndrome is the most commonly used term for this condition (Sharpe and Wessely, 2009).

*For the purposes of clarity, this protocol uses the term '**Chronic Fatigue Syndrome'**, however this should be considered to also represent the terms CFS/ME, ME/CFS and ME alone.*

1.2 Definition of Chronic Fatigue Syndrome

Chronic Fatigue Syndrome is chronic, debilitating mental and physical fatigue which is often triggered or exacerbated by activity. There is a wide variation in symptoms that individuals with CFS experience, but these commonly include joint and muscle pains, problems with concentration and memory, headaches, sore throat, tender cervical or axillary lymph nodes and unrefreshing sleep.

Due to the issues stated above with the two main diagnostic classification systems, the most widely used definition of Chronic Fatigue Syndrome is based on a working definition proposed by researchers into CFS (Sharpe and Wessely, 2009).

1.2.1 International Consensus Definition of Chronic Fatigue Syndrome

The International consensus definition of chronic fatigue syndrome (Fakuda et al., 1994) describes the disorder as having the following features:

1. Complaint of fatigue - of new onset, not relieved by rest, and lasting at least 6 months.

2. At least 4 of the following symptoms should be present:

    - Subjective memory impairment
    - Sore throat
    - Tender lymph nodes
    - Muscle and joint pain
    - Unrefreshing sleep
    - Malaise post exercise, lasting >24 hours

3. Impairment of functioning

4. Other conditions which may explain fatigue have been excluded.

It should be noted there are several issues with this definition (Sharpe and Wessely, 2009) including overlap with other medical and psychiatric illness, the exclusion of

fatigue in patients with organic disease, and the fact that individuals with CFS have such a varying pattern of symptoms.

Psychiatric disorders which have symptoms in common with CFS include:

- Depression
- Anxiety Disorders
- Neurasthenia
- Somatoform disorders (DSM-IV-TR classification for CFS is 'Undifferentiated somatoform disorder')

1.2.2 Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision (DSM-IV-TR) Classification

The DSM-IV-TR (American Psychiatric Association, 2000) classifies chronic Fatigue Syndrome as 'undifferentiated Somatoform disorder', with the following diagnostic criteria.

A. One or more physical complaints (e.g., fatigue, loss of appetite, gastrointestinal or urinary complaints).

B. Either:

(1) after appropriate investigation, the symptoms cannot be fully explained by a known general medical condition or the direct effects of a substance (e.g., a drug of abuse, a medication)

(2) when there is a related general medical condition, the physical complaints or resulting social or occupational impairment is in excess of what would be expected from the history, physical examination, or laboratory findings

C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

D. The duration of the disturbance is at least 6 months.

E. The disturbance is not better accounted for by another mental disorder (e.g., another Somatoform Disorder, Sexual Dysfunction, Mood Disorder, Anxiety Disorder, Sleep Disorder, or Psychotic Disorder).

F. The symptom is not intentionally produced or feigned (as in Factitious Disorder or Malingering).

1.2.3 International Classification of Diseases; 10th Edition (ICD-10) Classification

Although the intent is that each disorder can be classified in only one place in the ICD-10 classification system (WHO, 2007), in practicality 96% of the symptoms of

Chronic Fatigue Syndrome overlap between two codes in the diagnostic classification. The recommendation currently is that Chronic Fatigue Syndrome is classified as G93.3 (Benign myalgic encephalomyelitis), however the description of the other relevant code (F48) has been included below for reference.

G93.3 Benign myalgic encephalomyelitis – to be used where specific trigger such as a viral disease and/or where the symptoms do not fulfil the criteria for F48.0 (World Health Organization - UK Collaborating Centre, 2004).

F48.0 Neurasthenia – which has the following diagnostic features:

A. Either persistent and distressing complaints of increased fatigue after mental effort, or persistent and distressing complaints of bodily weakness and exhaustion after minimal effort;

B. At least two of the following:

- feelings of muscular aches and pains
- dizziness
- tension headaches
- sleep disturbance
- inability to relax
- irritability
- dyspepsia;

C. Any autonomic or depressive symptoms present are not sufficiently persistent and severe to fulfil the criteria for any of the more specific disorders in this classification.

It should be noted that the code F48.0 is little used in practice now (WHO, 2007).

2. Epidemiology

It is widely agreed that, despite the varied range of statistics presented by epidemiological studies on Chronic Fatigue Syndrome, prevalence cannot be stated precisely. This is due to differing definitions and diagnostic criteria which have been applied to the condition, and to the variation in measurement of severity levels and outcome measurement from study to study (Department of Health, 2003). Prevalence information also varies because many people do not seek formal help for the condition, or have not been correctly diagnosed with CFS (Merck Manuals, 2008).

Evidence suggests that the prevalence of CFS is underestimated – and may represent only a small proportion of the extent of CFS occurrence. The Centers for Disease Control and Prevention in the US (2006) suggest that 80% of the cases of CFS which occur are undiagnosed.

The prevalence of Chronic Fatigue Syndrome in Ireland has not been researched. Estimates suggest that CFS affects approximately 10-12,000 individuals in Ireland (Foras Aiseanna Saothair, 2009, Irish ME Trust, 2009). This represents a prevalence rate of 0.2-0.4% which correlates to the reported prevalence rate in other European countries.

Prevalence rates from other studies suggest rates of 0.006% to as high as 3.0% in primary care (Afari, 2003).

CFS affects four times as many women as men (NICE, 2007), but the prevalence is otherwise unaffected by race or socio-economic group.

In adults, onset is typically early twenties to mid forties age group. In children, onset is typically between 13-15 years (Irish ME Trust, 2009).

3. Aetiology

3.1 Overview

The aetiology of Chronic Fatigue Syndrome is controversial with the precise cause(s) and pathogenic mechanism(s) yet to be fully defined. Turnbull (2004) describes the disorder as 'as a spectrum of illness that is triggered by a variety of factors in people who have an underlying predisposition.' A central defect in the brain remains a strong possibility, though immunological abnormalities are increasingly being elucidated. These are not mutually exclusive. The multiplicity of proposed causes such as an infectious disease (e.g. infectious mononucleosis), altered stress hormone response, altered immune response, altered gene expression, sleep problems, alterations of mood, coping strategies, and toxin/chemical exposure give further weight to the argument that the composite term CFS/ME best describes this condition, and that it is a spectrum of disease.

3.2 Immune Dysfunction and Infection

Hickie et al (2006) concluded that 'prolonged fatigue states after infections are common and disabling' and that chronic fatigue syndrome was predicted 'largely by the severity of the acute illness, rather than by demographic, psychological, or microbiological factors'.

Infective agents which have been implicated include:

- Acute viral infections, such as infectious mononucleosis
- Latent infections, such as toxoplasmosis, Epstein-Barr virus or cytomegalovirus
- Chronic bacterial infections, such as borreliosis (Lyme disease)
- Chronic viral infections, such as HIV or hepatitis B or C

However, it has proved difficult to establish a link between CFS/ME and serology indicating past viral infection.

Environmental factors, abnormal physiological pathways and genetic pre-disposition are all likely to contribute to symptom production and response to illness in CFS/ME.

3.3 Physiology

There is good evidence that patient's with CFS/ME often exhibit elements of altered physiology. In particular these abnormalities can affect the neuro-endocrine and hypothalamic-pituitary-adrenal (HPA) axis function. Abnormalities include:

- A disturbance in circadian rhythms, particularly in relation to the secretion of melatonin and the hypothalamic maintenance of body temperature. This can

be similar to the changes often found in shift workers (Williams, 1996).

- Research into the hypothalamic-pituitary-adrenal axis (HPA) in CFS/ME patients suggests negative feedback and glucocorticoid receptor functions are increased, whilst adrenocorticotropic hormone (ACTH) and cortisol responses are decreased

- CFS/ME patients can have significantly raised serum levels of tryptophan resulting in increased availability of the rate-limiting precursor of serotonin (Badawy et al, 2005)

- CFS/ME suffers often show abnormalities in muscolo-skeletal and/or cardiovascular function.

However, it is not clear as to if these changes are the cause or the effect of CFS/ME (Nye and Crawley, 2007). For example, changes in physical condition in terms of skeletal, muscle or cardiovascular function could be due to periods of inactivity experienced by the CFS/ME sufferer (Fulcher, 2000).

3.4 Genetic

Classic twin studies have demonstrated a moderate heritable component to CFS/ME and other conditions of abnormal fatigue (Prins et al, 2006).

3.5 Life Events

Other stressful life events or difficulties may precede development of CFS/ME, particularly if the stress is ongoing. Other factors may contribute to prolonging the illness, for example poor nutritional uptake, or a concurrent mood disorder.

4. Diagnosis

Making a diagnosis of Chronic Fatigue Syndrome involves a certain amount of pragmatism (Sharpe and Wessely, 2009). The process of reaching a diagnosis often involves excluding other causes of organic and psychiatric disease, in order to be left with a recognisable set of characteristic symptoms which can best be explained by the diagnosis of CFS. In order to ensure all other forms of illness are excluded, a full medical and psychiatric assessment should be performed in all cases of suspected CFS (Sharpe and Wessely, 2009).

The National Institute for Clinical Excellence stress the importance of a diagnosis to the individual and their family, but state that any diagnosis of CFS should be considered as a provisional and working diagnosis only. This should be regularly reviewed to ensure that serious underlying disease does not remain undetected (Turnbull et al, 2004).

There are no specific laboratory tests or diagnostic evaluations that can be undertaken to confirm a suspected diagnosis of chronic disease syndrome, although there is a panel of investigations that should be routinely performed when the disorder is suspected ***(see section 4.4)***

4.1 Clinical Features

Although to a certain extent a diagnosis of "exclusion", CFS/ME may be recognised on clinical grounds with a careful and structured history.

Signs and symptoms that can be caused by other serious conditions should not be attributed to CFS/ME without consideration of alternative diagnoses or co-morbidities. These include:

- Localising/focal neurological signs
- Signs and symptoms of inflammatory arthritis or connective tissue disease
- Signs and symptoms of cardio-respiratory disease
- Significant weight loss; significant obesity
- Sleep apnoea
- Clinically significant lymphadenopathy
- Major depressive disorders
- Hypothyroidism.

For further information on differential diagnoses for Chronic Fatigue Syndrome please ***see section 5***.

Once serious conditions have been discounted, CSF/ME should be considered if the individual exhibits features which meet the diagnostic criteria outlined below. It should be noted that although this diagnostic description is generally used for CFS, it was originally formulated for research purposes. The definition is therefore recognised to be in adequate in some respects for clinical care.

Chronic Fatigue Syndrome should be considered if there is:

FATIGUE with all of the following features:

- New or had a specific onset (that is, it is not lifelong fatigue)
- Persistent and/or relapsing or recurrent pattern
- Unexplained by other conditions
- Has resulted in a substantial reduction in previous levels of occupational, educational, social or personal activities.
- Not substantially alleviated by rest

AND

Four or more of the following symptoms, which are current, have persisted for more than six months, and did not occur prior to the fatigue:

- Post-exertional malaise and/or fatigue after normal activity (typically for at least 24 hours, with slow recovery over several days)
- Difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep-wake cycle
- Muscle and/or joint pain that is multi-site and without evidence of inflammation
- Headaches of a new type, pattern or severity
- Painful lymph nodes without pathological enlargement
- Sore throat
- Cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing

(Fakuda et al, 1994)

4.2 Timing of Diagnosis

One of the conditions of the International Consensus definition (Fakuda et al, 1994), is that the fatigue experienced by the individual should have lasted at least 6

months.

A number of Authorities have commented that this time limit is not clinically appropriate, and that the six month time barrier should be considered as the end point by which the diagnosis should have been confirmed (Department of Health, 2003; Turnbull et al, 2007). NICE guidance recommends that referral to specialists in Chronic Fatigue Syndrome should be made immediately in people with severe symptoms, within three months for individuals who present with moderate symptoms, and within six months for individuals with mild symptoms.

These referral limits differ for paediatric and adolescent cases.

4.3 Physical Examination

A physical examination should be performed, but it should be noted that this may not reveal any abnormalities.

4.4 Mental State Examination

A thorough mental state examination should be performed to identify changes in mood, intellectual function, memory, and personality. Any symptoms of depression or anxiety should be identified.

The examination should aim to identify any psychiatric or neurological disorder that may account for the chronic fatigue. Referral for further psychological or neurological evaluation may be required.

4.5 Investigations

Where symptoms suggest CFS/ME, the following tests should usually be done:

- Urinalysis for protein, blood and glucose
- Full blood count
- Urea and electrolytes
- Liver function
- Thyroid function
- Erythrocyte sedimentation rate or plasma viscosity
- C-reactive protein
- Random blood glucose
- Serum creatinine

- Screening blood tests for gluten sensitivity
- Serum calcium
- Creatine kinase
- Assessment of serum ferritin levels (children and young people only) if indicated by full blood count results.

Serological testing is not required unless the history is suggestive of an infection.

Clinical judgement should be used to decide if additional investigations are required, in order to exclude other diagnoses.

4.6 Conditions Which Exclude Chronic Fatigue Syndrome

In addition to consideration of differential diagnoses, a number of criteria are defined as part of the International Consensus definition (Fakuda et al, 1994) which mean that the diagnosis of Chronic Fatigue Syndrome should be ruled out. These are:

- Any active medical condition which explains the presence of chronic fatigue e.g. hypothyroidism
- Any previous medical condition which may be unresolved and explain ongoing fatigue e.g. hepatitis infection
- Any past or present diagnosis of psychiatric conditions which may explain the fatigue e.g. depressive disorder, anorexia etc.
- Alcohol or other substance abuse within 2 years before the onset of the chronic fatigue and at any time afterward
- Severe obesity (defined as a body mass index (weight kilograms/[height in meters]^2) of greater than 45)

4.7 Severity of Disorder

The individual may report different signs and symptoms dependent on the severity of the condition. The degree to which CFS/ME affects a person's functioning and daily life has been the basis for grading CSF/ME as mild, moderate or severe (Carruthers et al, 2003):

Mild

People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks albeit with occasional difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.

Moderate

People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe

People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

5. Differential Diagnosis and Comorbidity

5.1 Differential Diagnosis

There is a fairly lengthy list of conditions which should be considered as a potential differential diagnosis for Chronic Fatigue Syndrome. These conditions include:

Infectious

- Epstein-Barr virus
- Lyme disease
- Tuberculosis
- HIV/AIDS
- Hepatitis B or C

Endocrine

- Hyperthyroidism
- Hypothyroidism
- Addison's disease
- Adrenal insufficiency
- Cushing's syndrome
- Diabetes mellitus

Psychiatric

- Psychotic disorder (bipolar disorder, schizophrenia)
- Delusional disorders
- Depressive disorders
- Seasonal affective disorder (SAD)
- Dementia
- Eating disorders (anorexia nervosa, bulimia nervosa)
- Alcohol or substance abuse

Neuropsychological

- Multiple sclerosis
- Parkinson's disease

Haematological

- Anaemia
- Lymphoma

Rheumatological

- Rheumatoid arthritis
- Fibromyalgia
- Polymyalgia rheumatica

Respiratory

- Breathing disorders (hypoxia, hypercapnia)
- Sleep syndromes (narcolepsy, sleep apnoea)
- Nocturnal asthma

Toxicity

- Toxic exposure (heavy metals or lead)
- Irradiation

Other

- Endocarditis
- Immune or inflammatory disease
- Malignancy
- Metabolic/nutritional disorder
- Neurally-mediated hypotension
- Neuromuscular disorders
- Somatoform disorder
- Systemic lupus erythematosus
- Pharmacological side effects (e.g. antihistamines)

5.2 Comorbidity

Individuals with Chronic Fatigue Syndrome often have other accompanying conditions, resulting in a complex clinical picture which may hinder diagnosis.

Two of the most common comorbid disorders, depression and fibromyalgia syndrome, share a number of symptoms with CFS/ME. Some authors have described these as 'overlapping' diseases.

Studies have indicated there is a close link between depression and chronic fatigue syndrome, although as CFS shares some symptoms with depression the exact relationship between the two disorders is not clear. Studies indicate around 66% of individuals with CFS have symptoms of major depressive illness with 50% of individuals reporting at least one episode of major depression.

Other conditions which commonly exist with CFS include:

- Sleep disorders (40-80% of patients – but may be a symptom of CFS rather than a comorbid condition) (McPhee and Papadakis, 2009)
- Myo-fascial pain syndrome (MPS)
- Temporomandibular joint (TMJ) syndrome
- Irritable bowel syndrome (IBS)
- Irritable bladder syndrome , interstitial cystitis
- Raynaud's syndrome
- Prolapsed mitral valve
- Migraine
- Allergies and/or multiple chemical sensitivities
- Hashimoto's thyroiditis

6. Treatment

Although there is no specific treatment for CFS, most individuals will recover to some extent, regaining some or all of their functional ability. However, this is likely to be over a period of months or years. Treatment for Chronic Fatigue Syndrome focuses on educating individuals on rehabilitation, avoidance of precipitating factors and easing the symptoms.

Chronic Fatigue Syndrome is a disorder where 'management' is perhaps a more appropriate term than 'treatment'.

6.1 Management Options for Chronic Fatigue Syndrome

Management strategies focus on four main areas:

- Pharmacological therapies aimed at symptom control
- Psychological therapies
- Lifestyle adjustments and strategies to adjust for fatigue and minimise exacerbation of the syndrome
- Exercise therapies

Evidence has shown that early diagnosis, balancing rest with activity, use of medication to control certain symptoms, and self-help measures can all help to varying degrees. Other therapies which are useful include Cognitive behavioural therapy (CBT), graded exercise therapy (GET), activity management, pacing, sleep management and relaxation, supported by pharmacological interventions, diet and nutrition and complementary therapies.

6.2 Pharmacological interventions

Pharmacological interventions should be aimed at addressing or controlling the symptoms which are experienced by individuals with Chronic Fatigue Syndrome as there are no medication therapies which will directly treat the syndrome itself.

The evidence base for pharmacological interventions for Chronic Fatigue Syndrome has been assessed by the National Institute for Clinical Excellence, which concluded most studies of this area were small, with very few suggesting a beneficial effect (Turnbull et al, 2007). Significant improvements for individuals with fatigue were found in a trial of dexamphetamine but reduced food consumption was a side effect.

For individuals who have disturbed sleep or suffer from pain, evidence suggests that low-dose tricyclic antidepressants, specifically amitriptyline, can be effective. However, these are contraindicated in individuals already taking selective serotonin reuptake inhibitors (SSRIs) due to the potential for serious adverse interactions. Individuals may well find the suggestion of a trial of antidepressant medication unwelcome – this may reinforce a view that their disorder is seen as psychological

or imaginary (Sharpe and Wessely, 2009).

NICE have made a number of recommendations with respect to pharmacological interventions which should NOT be used for the treatment of Chronic Fatigue Syndrome:-

- Monoamine oxidase inhibitors (such as meclobamide)
- Glucocorticoids (such as hydrocortisone)
- Mineralocorticoids (such as fludrocortisone)
- Dexamphetamine (used in ADHD)
- Methylphenidate (used in ADHD)
- Thyroxine
- Antiviral agents.

It should be noted that, although there is no evidence base to support this, there is anecdotal evidence that individuals with CFS report greater intolerance and increased side effects to medication. Consideration should be given to starting any pharmacologic treatment at a lower dose than usual clinical practice, and increasing the dose slowly in order to avoid intolerance or untoward side effects (Turnbull et al, 2007)

6.3 Pain Management

A number of individuals with Chronic Fatigue Syndrome may suffer chronic pain. If this is a predominant feature, referral to a pain management clinic should be considered.

6.4 Cognitive Behavioural Therapy

Cognitive Behavioural Therapy is a specific psychological therapy, based on underlying theoretical principles, with a broad evidence base across a variety of conditions. This therapy aims to reduce the levels of symptoms, disability and distress associated with Chronic Fatigue Syndrome. CBT or psychological approaches to this disorder do not imply that symptoms are psychological, 'made up' or in the patient's head, but is the most common treatment for Chronic Fatigue Syndrome.

It should be noted however, that although this therapy is used with many conditions (for example, depression, eating disorders, cardiac rehabilitation, diabetes, chronic pain) it is not a therapy which is effective for all individuals, and requires individuals who are skilled in the delivery of CBT techniques specifically for Chronic Fatigue Syndrome (Sharpe and Wessely, 2009).

CBT aims to address the factors which may be maintaining the individual's

condition, not the underlying causes. The treatment involves planned periods of activity and rest, a gradual increase in exercise and activity, and looking at beliefs and assumptions which may have an impact on the individual's psychological health.

The duration of therapy is usually around 12-16 sessions and may take place over six months to a year. One-to-one therapy is advised (Turnbull et al, 2009)

Indicators predictive of poor outcome from CBT include passive activity levels, poor social and occupational function prior to the onset of fatigue (Sharpe, 1998), when an individual excessively focuses on symptoms (Prins, 2001). There is also some evidence to indicate that individuals who retire or claim disability benefit during the period of CBT will gain less benefit from the therapy (Deale, 1998).

6.5 Graded Exercise Therapy

Graded Exercise Therapy is a structured exercise plan, where a achievable baseline of physical activity is agreed and gradually increased in order to achieve aerobic activity over time.

Individuals are advised not to exceed the planned activity level. This therapy should be undertaken by a suitably trained practitioner with experience of working with Chronic Fatigue Syndrome. If the individual exceeds the planned activity levels, or GET is introduced or progressed at too high a level, the individual can experience an exacerbation to their symptoms. There is some evidence to state there is a high drop out level with GET – possibly as individuals with more severe Chronic Fatigue Syndrome find any form of exercise problematic (Department of Health, 2001; Turnbull et al, 2007)

6.6 Activity Management

Activity Management aims to provide a structured plan to balance different activities, rest and sleep. The plan may be on a daily or weekly basis and will look to spread demanding activities over a longer period e.g. a week, and to break tasks down into small manageable parts (Department of Health 2001; Turnbull et al, 2007).

6.7 Pacing

Pacing is defined as energy management, with the aim of planning physical and cognitive function in order to balance activity and rest and avoid overexertion. The thought is that if an individual uses the energy they do have effectively, then over a longer period their energy levels may increase

There are a number of different definitions of pacing.

There is no evidence to support pacing as a therapy, although it is anecdotally reported by individuals to be of use (Turnbull et al, 2007). However, there is a large randomised controlled clinical trial taking place which aims to compare pacing with CBT and graded exercise therapy in individuals with Chronic Fatigue Syndrome.

The findings of the trial are due to be reported in late 2009. See www.pacetrial.org. .

6.8 Sleep Management

Sleep Management includes techniques such as sleep hygiene, which uses behavioural approaches, and changes in environmental conditions which can be introduced to improve the quality of sleep.

Although individuals with Chronic Fatigue syndrome benefit from rest periods, day time sleeping should not be encouraged as this will further exacerbate disordered sleep patterns which are often experienced by people with CFS.

6.9 Relaxation

Relaxation therapies can be a helpful strategy for people with Chronic Fatigue Syndrome. There are a number of different techniques which can be of use for helping with sleeping problems, stress or anxiety and the management of pain.

Relaxation training and memory aids such as organisers and written resource manuals may also be helpful for addressing cognitive problems.

6.10 Nutrition and Diet

Dietary interventions including general supplements, pollen extract, medicinal mushrooms, acclydine (an alkaloid which stimulates the pituitary release of growth hormone), amino acids, essential fatty acid supplements and magnesium supplements have been shown to have unknown effectiveness.

A group with post-viral syndrome did report an overall beneficial effect with essential fatty acid supplements with improvements in symptom measures.

Magnesium supplements had an overall positive effect of improvements in measures of energy and pain, emotional reactions, general health and laboratory measures, but not in sleep, physical mobility or social isolation.

Individuals with CFS may have a variety of issues with nutrition due to their condition (Turnbull et al, 1997), and should be referred to a dietician where appropriate.

These issues include:

- Weight gain due to lack of mobility
- Weight loss due to poor nutrition
- Difficulty eating due to fatigue and/or pain
- Difficult or painful swallowing, sore throat
- Nausea or sickness making food either undesirable or physically difficult to

eat

- Irritable bowel, digestion issues
- Food intolerances leading to a restricted diet
- Disturbed sleep patterns causing meal patterns to be disrupted
- The need for carers to help with food purchase, preparation and feeding.

In extreme cases individuals may require tube feeding.

7. Prognosis

The prognosis for individuals with Chronic Fatigue Syndrome is variable. People with mild illness may recover spontaneously, or with some general advice or a limited treatment programme over a six month period. These people are likely to be treated in a general practice setting and recover before specialist referral is required.

The majority of studies into the prognosis of Chronic Fatigue Syndrome have concentrated on individuals being treated at specialist clinics (Reid et al, 2008). These studies show a wide variation in recovery rates. Full recovery is thought to occur in only 5-10% of individuals, with a further 40-60% achieving a significant reduction in their symptoms over time (CDC, 2006, Cairns and Hotopf, 2005; Reid et al, 2008)

7.1 Indicators of Good Prognosis

Indicators of a good prognosis are:

- Early diagnosis and early initiation of treatment
- Male sex
- A definite history of an acute viral illness (e.g. glandular fever)
- Mild disability and few symptoms
- Clinical features showing a pattern of evolution towards functional recovery
- A management approach which facilitates a gradual return to normal levels of activity.

7.2 Indicators of Poor Prognosis

While indicators of a poor prognosis include:

- Female
- Onset of symptoms without any clear precipitating factor,
- Clinical course characterised by severe and unremitting symptoms,
- Severe and persistent disability
- Comorbid significant medical conditions (e.g. fibromyalgia, fluid retention syndrome or irritable bowel syndrome)
- Comorbid psychiatric conditions (e.g. depression and anxiety)
- A complex background of adverse psychological and social factors

- Management of the condition using excessive exercise or excessive rest

The course of recovery is usually variable. Individuals will experience a pattern of relapse and remission which can vary significantly in their duration and severity. Long term significant disability is not uncommon.

Although morbidity may be significant, there is no associated increase in mortality (Reid et al, 2008).

8. Information Gathering at the In Person Assessment

8.1 Assessing the Claimant

The examining doctor should consider the information on file, informal observations, medical and psychiatric history, medication and other treatments, typical day, physical examination and mental state examination.

Variability is an important factor to take into consideration when assessing someone with CFS/ME. An attempt should be made to obtain a complete picture that includes a description of the claimant's functional ability most of the time, as well as their best and worst days.

8.2 Physical examination

As seen in the earlier chapters, the diagnosis of CFS/ME is based mainly on the reported symptoms, and in mild or moderate cases there will often be no significant clinical findings on examination.

In severe cases, a degree of muscle wasting may be expected in the limbs.

Remember that significant clinical findings such as neuropathy, arthropathy, glandular swelling and obesity would normally preclude a diagnosis of CFS/ME.

Informal observations may confirm slowness of movement and cognition and the corresponding need for assistance.

8.3 Mental Health Assessment

It is important to complete an appropriate mental health assessment in individuals presenting with CFS/ME. A detailed mental health history should be taken to include diagnosis, treatment, periods of hospitalisation etc. This may provoke a hostile response from claimants who consider their condition to be wholly physical in nature and must always be administered tactfully with an appropriate explanation.

8.3.1 Assessment of Ability/Disability

***The key areas to address in ability/disability assessment medicine relate mainly to functional ability in relation to day to day and workplace activities*.**

The recommended approach to assessing an individual's functional ability is to ask them to describe their average day. Taking a history of a claimant's average day, from the moment they awake to how they sleep, will allow an evaluation of the nature and severity of their disability in relation to simple tasks in terms of comprehension, learning, concentration, memory and motivation. It will also provide

an indication of any need for guidance, prompting or supervision. This information along with the other evidence obtained or provided will facilitate an overall assessment of disability in relation to the criteria for various scheme benefits. This analysis stage is covered further in chapter 9 of the protocol.

A number of areas are suggested under the four key headings below that should be explored during the assessment, where relevant, through open questioning and observation.

Completion of tasks

- Answering the phone
- Setting an alarm clock
- Operating domestic appliances
- Reading a magazine or watching TV
- Driving a car
- Hobbies and Interests
- Accidents in the home – hazard awareness.

Daily living

- Rising, washing, dressing
- Care over appearance/Self-Neglect
- Frequent mood fluctuation causing distress or panic
- Need for alcohol early in the day
- Sleep pattern.

Coping with Pressure and Change

- History of Work related stress
- Concerns that work may aggravate illness
- Symptoms of fear and panic
- Avoidance of stressful activities – going out, driving a car
- Effect of changes in routine
- Fatigue/Apathy or Disinterest – effect on activities.

Interaction with People

- Capability for self care
- Irritability/Disruption/Aggression
- Communicating with people
- Fear of going out alone
- Avoidance of the company of other people.

9. Analysis of Effect on Functional Ability

Eligibility to the Department of Social and Family Affairs various Illness-related schemes and Activation Programme, is determined primarily by the degree of Ability/Disability and its expected duration.

The degree of Ability/Disability assessed, using the following Indicators, can be depicted on the Ability/Disability Profile illustrated below.

9.1 Indicators of Severity of Ability/Disability

Normal

- In the recovery phase of CFS/ME
- Sleeping well at night and not during the day
- No restriction on walking distance or time
- Able to carry out shopping and routine household tasks

Mild

- Remain mobile and self-caring
- Personal grooming and hygiene is unaffected
- Continuing to perform some light household tasks with occasional difficulty
- May need to take time out and rest to cope with activities
-

Moderate

- Reduced mobility except for short distances
- Restriction in performing all activity of daily living
- Variability will still allow peaks and troughs in symptom levels
- Unable to attend work , school or college
- Will need frequent rest periods and often sleep for 1-2 hours in the afternoon
- Sleep at night is usually disturbed and of poor quality

Severe

- Only able to carry out minimal self-caring tasks (wash face, clean teeth)
- Significant problems with mobility even moving around indoors
- Prolonged recovery period needed after any undue activity
- Impaired concentration affects ability to perform simple tasks
- Extremely sensitive to bright light and loud noises

Profound

- Only mobile in a wheelchair
- Spend most of their time in bed
- Inactivity has resulted in muscle wasting

9.2 Ability/Disability Profile

Indicate the degree to which the Claimant's condition has affected their ability in ALL of the following areas.					
	Normal	Mild	Moderate	Severe	Profound
Mental health/Behaviour	☐	☐	☐	☐	☐
Learning/Intelligence	☐	☐	☐	☐	☐
Consciousness/Seizures	☐	☐	☐	☐	☐
Balance/Co-ordination	☐	☐	☐	☐	☐
Vision	☐	☐	☐	☐	☐
Hearing	☐	☐	☐	☐	☐
Speech	☐	☐	☐	☐	☐
Continence	☐	☐	☐	☐	☐
Reaching	☐	☐	☐	☐	☐
Manual dexterity	☐	☐	☐	☐	☐
Lifting/Carrying	☐	☐	☐	☐	☐
Bending/Kneeling/Squatting	☐	☐	☐	☐	☐
Sitting	☐	☐	☐	☐	☐
Standing	☐	☐	☐	☐	☐
Climbing stairs/Ladders	☐	☐	☐	☐	☐
Walking	☐	☐	☐	☐	☐

10. Summary of Scheme Criteria

Scheme eligibility criteria are maintained on the DSP website and are accessible from the following links:

- **Carer's Allowance**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/carers_all.aspx
- **Carer's Benefit**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/carers_ben.aspx
- **Disability Allowance**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/disall.aspx
- **Disablement Benefit**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/oib_disableb.aspx
- **Domiciliary Care Allowance**
  http://www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/DomiciliaryCareAllowance/Pages/DomiciliaryCareAllowance.aspx
- **Illness Benefit**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/illben.aspx
- **Injury Benefit**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/oib_injuryb.aspx
- **Invalidity Pension**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/invalidity.aspx
- **Respite Care Grant**
  http://www.welfare.ie/EN/OperationalGuidelines/Pages/respitegrant.aspx

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